State of South Dakota

SEVENTY-SIXTH SESSION LEGISLATIVE ASSEMBLY, 2001

175E0028

SENATE JUDICIARY COMMITTEE ENGROSSED NO. ${\bf SB~1}$ - 01/19/2001

Introduced by: Senators Madden and Ham and Representatives McCoy and Slaughter at the request of the Interim Judiciary Committee

- 1 FOR AN ACT ENTITLED, An Act to require written informed consent before genetic testing.
- 2 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF SOUTH DAKOTA:
- 3 Section 1. Terms used in this Act mean:
- 4 (1) "Genetic information," information derived from a genetic test about a gene, gene
 5 product, or inherited characteristic;
- "Genetic test," a test of human DNA, RNA, chromosomes, or genes performed in 6 (2) 7 order to identify the presence or absence of an inherited variation, alteration, or 8 mutation which is associated with predisposition to disease, illness, impairment, or 9 other disorder. Genetic test does not mean a routine physical measurement; a 10 chemical, blood, or urine analysis; a test for drugs or HIV infection; any test 11 commonly accepted in clinical practice; or any test performed due to the presence of 12 signs, symptoms, or other manifestations of a disease, illness, impairment, or other 13 disorder;
 - (3) "Predictive genetic test," a genetic test performed for the purpose of predicting the

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1 future probability that the person tested will develop a genetically related disease or 2 disability. 3 Section 2. No person may order or perform a predictive genetic test without first obtaining 4 the written, informed consent of the person to be tested. For purposes of this section, written, 5 informed consent consists of a signed writing executed by the person to be tested or the legally 6 authorized representative of the person to be tested that includes, at a minimum, all of the 7 following: 8 (1) The nature and purpose of the predictive genetic test; 9 (2) The effectiveness and limitations of the predictive genetic test; 10 (3) The implications of taking the predictive genetic test, including, the medical risks and 11 benefits; 12 (4) The future uses of the sample taken from the person tested in order to conduct the 13 predictive genetic test and the information obtained from the predictive genetic test; (5) 14 The meaning of the predictive genetic test results and the procedure for providing 15 notice of the results to the person tested; and 16 (6) A listing of who will have access to the sample taken from the person tested in order 17 to conduct the predictive genetic test and the information obtained from the predictive 18 genetic test, and the person's right to confidential treatment of the sample and the 19 information. 20 Section 3. If a person to be tested or the person's legally authorized representative signs a 21 copy of the informed consent form developed pursuant to section 2 of this Act, the person 22 obtaining the informed consent shall give the person to be tested a copy of the signed informed 23 consent form and shall include the original signed informed consent form in the medical record 24 of the person tested.

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1 Section 4. Nothing in this Act alters the ability to perform genetic tests done in pursuance

2 of a lawful criminal investigation or court order.